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IN THE

Supreme Court of the United States

OCTOBER TERM, 1989

NANCY BETH CRUZAN, by her parents and co-guardians, LESTER L. and JOYCE CRUZAN,

Petitioners,

—v.—

DIRECTOR OF MISSOURI DEPARTMENT OF HEALTH, and ADMINISTRATOR OF THE MISSOURI REHABILITATION CENTER AT MT. VERNON,

Respondents,

—v.—

THAD C. MCCANSE, Guardian ad litem,

Respondent.

ON A WRIT OF CERTIORARI TO THE SUPREME COURT OF THE STATE OF MISSOURI

BRIEF OF *AMICUS CURIAE* CONCERN FOR DYING IN SUPPORT OF PETITIONERS

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September 1, 1989

QUESTIONS PRESENTED

1. Is There a Fundamental Constitutional Right to Refuse Medical Treatment?
2. Is Artificial Alimentation a Form of Medical Treatment That Individuals Can Refuse?
3. Do Individuals Automatically Lose Their Right to Refuse Medical Treatment When They Become Incompetent, or Can Others Exercise it on Their Behalf?

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INTEREST OF *AMICUS CURIAE*

Concern for Dying (hereinafter "Concern") is a national, private, not-for-profit educational council organized and incorporated in 1967 to address the legal, medical, ethical and social issues involved in the care and treatment of dying patients, which include respect for a patient's right to forgo life-sustaining treatment. Since its founding, Concern has distributed over eight million copies of the Living Will, the document first and most frequently associated with an individual's right to refuse life-sustaining treatment.

Through educational and other programs, Concern supports the proposition that decisions to apply, withhold or withdraw medical care and technology are a matter of personal, not medical, judgment, and that such decisions should be made in accordance with a patient's wishes, values and beliefs.

Concern has participated as *amicus curiae* in cases concerning these issues and has contributed in an advisory capacity to major studies of these issues. Because of its expertise in the practical issues regarding terminal care decisionmaking and the care of patients who wish to forgo further treatment, Concern respectfully submits this brief to provide the Court with information pertaining to both the legal questions and the ethical, medical and social aspects of the issues that this case raises.[1]

SUMMARY OF THE ARGUMENT

This is a straightforward "right to refuse treatment" case, not a novel "right to kill" case. Dozens of cases like this one have been litigated across the country since the 1976 case of Karen Ann Quinlan, where the New Jersey Supreme Court concluded that Karen Quinlan's parents could refuse life-sustaining treatment on her behalf. When it first appeared the *Quinlan* case was widely hailed, and it has been consistently followed by other courts. Many, if not most, Americans have said at one

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1 The letters consenting to the participation of *amicus curiae* in this case are on file with the Clerk of the Court.

time or another, "I hope I never end up like Karen Quinlan," meaning they hope they are never in a permanent coma, kept alive by machines; that they will be permitted to die naturally. The case of Nancy Cruzan raises issues just like those raised in the case of Karen Ann Quinlan, except that while Ms. Quinlan required both a mechanical ventilator and artificial alimentation to live, Ms. Cruzan requires only the latter. Both young women were unexpectedly injured, both in a persistent vegetative state, both left only general statements of their wishes, and in both cases, their parents sought to have medical treatment ended. The inventions of new medical technologies have seemed to some to require the invention of new laws, as if medical technologies, not individual citizens, had rights. But new laws are not needed. Medical care has always been based on consent, not compulsion. Individuals have a common law and a fundamental constitutional right to refuse treatment, and this right must extend to artificial alimentation to be meaningful in the context of modern medicine. The state does have an interest in preserving life, but that interest is never greater than the individual's own interest in making personal treatment decisions.

Citizens do not lose their common law and constitutional rights simply by becoming incompetent. On the other hand, incompetent patients are not able to personally exercise their right to refuse treatment. In recognition of this many individuals have resorted to executing "living wills" to record their treatment preferences, and to appointing surrogates to make treatment decisions for them in case of incompetence. These decisionmaking mechanisms have been widely endorsed by both courts and legislatures. But what if someone is suddenly rendered permanently comatose and has not made her wishes specifically known regarding the type of treatment that would be required to maintain her in her permanent coma? We can take one of three courses: always provide treatment, never provide treatment, or make a decision based either on what the individual would want (substituted judgment) or, if this cannot be persuasively determined, on what is in the person's best interests. *Amicus* suggests that always treating everyone for the good of the state, as suggested by the Missouri Supreme Court, is an

insensitive rule that fails to give adequate consideration to values other than autonomy, including personal dignity and family decisionmaking. The evidence in this case was sufficient for the trial judge to conclude as a fact that Nancy Cruzan would decide to order artificial alimentation discontinued if she were to speak to us. That the Cruzans went to court for this decision hardly constitutes "unfettered autonomy." Accordingly, the decision of the Missouri Supreme Court should be reversed and the trial court's decision reinstated. In the alternative, the case should be remanded to the Missouri Supreme Court so it can develop a decisionmaking procedure that permits guardians to make treatment decisions consistent with the known wishes or best interests of their wards, as the law permits everywhere but Missouri.

I. COMPETENT ADULTS HAVE A COMMON LAW AND CONSTITUTIONAL RIGHT TO REFUSE MEDICAL TREATMENT

The Missouri Supreme Court's decision to deny the petition of Nancy Cruzan's parents and guardians to exercise her right to refuse medical treatment on her behalf was an almost inevitable result of the court's misstatement of the case as a "right to kill" or "right to die" case, rather than a "right to refuse treatment" case. In the court's words, "This is a case in which we are asked to allow the medical profession to *make Nancy die* by starvation and dehydration . . . We are asked to hold that . . . [Nancy Cruzan] must die." *Cruzan v. Harmon*, 760 S.W.2d 408, 412 (1988) (emphasis added). The reason for this unique characterization of the case seems to be the Missouri Supreme Court's recognition of the centrality of the right to refuse treatment in both common and constitutional law, and of the comparative illegitimacy of the "right to die." The attempt, however, fails. This case is just like the Karen Quinlan case and similar to the more than fifty other cases from sixteen states that the Missouri court summarily dismisses. It is a case where an adult's right to refuse medical treatment is being contested. That this right is at the core of liberty in the United States

requires little elaboration, and it is thus not surprising that a court seemingly determined to compel medical treatment would seek to distance its opinion from the well-established right of the individual to refuse it.

The Missouri Supreme Court itself notes that "[t]he common law recognizes the right of individual autonomy over decisions relating to one's health and welfare," *id.*, at 416, and further, that the doctrine of informed consent has been developed by the courts "in recognition of the value society places on a person's autonomy and as the primary vehicle by which a person can protect the integrity of his body." *Id.* at 417. The common law right to refuse treatment is not disputed. The Missouri court is less enthusiastic about including the right to refuse medical treatment under the "right of privacy," but ultimately does not reject this conclusion. Instead the court attempts to narrow the constitutional right to refuse treatment by saying, "We carry grave doubts as to the applicability of privacy rights to decisions to terminate the provision of food and water to an incompetent patient." *Id.* at 418.

Amicus respectfully suggests that this Court harbor no such doubts on this central issue. Under any reasonable method of interpreting the Constitution, the right to refuse invasive medical treatment is inherent in the fundamental right of liberty, a right expressly acknowledged by the New Jersey Supreme Court's *Quinlan* ruling in 1976, but a feature of Anglo-American law since liberty began. Concerning Karen Quinlan's constitutional right to refuse treatment the New Jersey Supreme Court wrote simply:

> Presumably [the constitutional right of privacy] is broad enough to encompass a patient's decision to decline medical treatment under certain circumstances, in much the same way as it is broad enough to encompass a woman's decision to terminate pregnancy under certain conditions.

Matter of Quinlan, 70 N.J. 10, 40, 355 A.2d 647, 663 (1976)

Every appellate court since 1976 that has reached the constitutional issue has agreed with this conclusion. *Amicus* suggests

that so little effort was expended by the New Jersey Supreme Court and the others that have followed its lead on this issue, precisely because the fundamental constitutional status of the right to refuse treatment is essentially self-evident. Individuals cannot be treated against their will without forcibly restraining them and depriving them of their liberty; and invading their bodies physically against their will demeans them and strips them of their dignity. Annas, *The Rights of Patients*, 83-84 (2d ed., 1989).

Accordingly, the law acknowledges that patients' wishes control decisions concerning chemotherapy, radiation treatments, amputations and other surgeries, respirators, burn treatment, cardiopulmonary resuscitation, renal dialysis and artificial feeding. *In re Farrell*, 108 N.J. 335, 529 A.2d 404 (1987); *Satz v. Perlmutter*, 362 So.2d 160 (Fla. Dist. Ct. App. 1978), *aff'd* 379 So.2d 359 (Fla. 1980); *In re Doe*, 45 Pa. D. & C. 3d 371 (Phila. C. P. 1987); *In re Yetter*, 62 Pa. D. & C. 2d 619 (Northampton C.P. 1973); *Bartling v. Superior Court*, 163 Cal. App.3d 186, 209 Cal. Rptr. 220 (1984); *Bouvia v. Superior Court*, 179 Cal. App.3d 1127, 225 Cal. Rptr. 297 (1986); *In re Lydia E. Hall Hospital*, 116 Misc.2d 477, 455 N.Y.S.2d 706 (Sup. Ct. 1982); Maynard and Muth, "The Choice to End Life as a Ventilator-Dependent Quadriplegic", 68 Arch. Phys. Med. Rehab. 862 (1987); Neu and Kjellstrand, "Stopping Long-Term Dialysis: An Empirical Study of Withdrawal of Life-Supporting Treatment", 314 N. Eng. J. Med. 14 (1986); Roberts and Kjellstrand, "Choosing Death: Withdrawal from Chronic Dialysis Without Medical Reason", 223 Acta Med. Scand. 181 (1988); Imbus and Zawacki, "Autonomy for Burned Patients When Survival is Unprecendented", 297 N. Eng. J. Med. 308 (1977); Annas, *et al.*, "The Right to Refuse Treatment: A Model Act", 73 Am. J. Pub. Health 918 (1983); President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (hereinafter "President's Commission"), *Deciding to Forego Life-Sustaining Treatment* (hereinafter *Deciding to Forego*), 43-60 (1983). Informed consent protects more than self-determination. Its values include: (1) protection of the patient's dignity

as a human being; (2) avoidance of fraud and duress; (3) encouragement of professional self-scrutiny; and (4) facilitating rational decisionmaking. Katz and Capron, *Catastrophic Diseases: Who Decides What?*, 82-90 (1982 ed.). It is fundamental to our way of life. President's Commission, *Making Health Care Decisions*, Vol. I, 44-45 (1982); Pennock, *Democratic Political Theory*, 239-241, 266-268 (1979).

Under those cases that define personal liberty and acknowledge a fundamental right of privacy, the individual's interest in controlling which medical procedures will be administered to him—regardless of other factors to be balanced in reaching a decision to forgo treatment in a given case—is a fundamental right protected under the liberty interest of the Fourteenth Amendment. *Jacobson v. Massachusetts*, 197 U.S. 11, 26 (1905); *Olmstead v. U.S.*, 277 U.S. 438, 478 (1928) (Brandeis, J. dissenting); *Skinner v. Oklahoma*, 316 U.S. 535 (1942); *Griswold v. Connecticut*, 381 U.S. 479 (1965); *Eisenstadt v. Baird*, 405 U.S. 438 (1972); *Roe v. Wade*, 410 U.S. 113, 152-53 (1973); *Cleveland v. Board of Education v. LaFleur*, 414 U.S. 632, 639-40 (1974); *Paul v. Davis*, 424 U.S. 693, 710-713 (1976); *Whalen v. Roe*, 429 U.S. 589, 598-600 (1977); *Maher v. Roe*, 432 U.S. 464, 471-73 (1977); *Harris v. McRae*, 448 U.S. 297, 312, n.18 (1980); *Akron v. Akron Center for Reproductive Health*, 462 U.S. 416, 426-27 (1982). This Court recently reaffirmed that a "physical intrusion, penetrating beneath the skin, infringes [a reasonable] expectation of privacy." *Skinner v. Railway Labor Executives' Association*, 57 U.S. L.W. 4324, 4328 (1989); *see also*, *Schmerber v. California*, 384 U.S. 757, 772 (1966); *Rochin v. California*, 342 U.S. 165, 174 (1965). The gastrostomy tube that invades Nancy Cruzan's body, without either her consent or that of her family but solely at the behest of the State of Missouri, invades her constitutionally protected interest in liberty and privacy. *Gray v. Romeo*, 697 F. Supp. 580, 584-86 (D.R.I. 1988); *Rasmussen v. Fleming*, 154 Ariz. 207, 215-16, 741 P.2d 674, 681-82 (1987); *Barber v. Superior Court*, 147 Cal. App.3d 1006, 195 Cal. Rptr. 484 (Ct. App. 1983); *Bartling v. Superior Court*, *supra*, 163 Cal. App.3d at 195, 209 Cal. Rptr. at 225; *Bouvia v. Superior Court*, *supra*,

179 Cal. App.3d at 1137-1138, 225 Cal. Rptr. at 301; *McConnell v. Beverly Enterprises-Connecticut, Inc.*, 209 Conn. 692, 553 A.2d 596 (1989); *John F. Kennedy Memorial Hospital v. Bludworth*, 452 So.2d 921, 923-24 (Fla. 1984); *In re L.H.R.*, 253 Ga. 439, 321 S.E.2d 716 (1984); *In re Quinlan*, 70 N.J. 10, 355 A.2d 647 (1976).[2]

While *amicus* agrees with the courts that have concluded that the constitutional right of privacy encompasses the right to refuse medical treatment, one can reach the conclusion that the right to refuse medical treatment is a fundamental right without even discussing the right to privacy. This is because the right to determine who will do what with one's body is "deeply rooted in this nation's history and tradition" and is "implicit in the concept of ordered liberty."

> It is an established part of our constitutional jurisprudence that the term 'liberty' in the Due Process Clause extends beyond freedom from physical restraint . . . [but] the Due Process Clause affords only those protections "so rooted in the traditions and conscience of our people as to be ranked as fundamental."

Snyder v. Massachusetts, 291 U.S. 97, 105 (1934). *Michael H. v. Gerald D.*, 57 U.S.L.W. 4691, 4694 (1989).

The right to refuse treatment meets these criteria. It has been an enduring principle of American law and medical practice that:

> [Every person] of adult years and sound mind has a right to determine what shall be done with his body; and a surgeon who performs an operation without his patient's consent commits an assault for which he is liable in damages.

Schloendorff v. Society of New York Hospital, 211 N.Y. 125, 129-30, 105 N.E.2d 92, 93 (1914), *and see* Faden and Beau-

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2 The Ninth Amendment, intended to protect against "the most dangerous political heresies", Story, *Commentaries on the Constitution of the United States*, 711 (1987 ed.), also guarantees the liberties denominated under the right of privacy. *Griswold*, at 492 (Goldberg, J. concurring).

champ, *A History and Theory of Informed Consent* (1986); President's Commission, *Making Health Care Decisions*, Vol. I (1982).

Even in the case most often cited for the proposition that the state has a sufficient interest in protecting the health and safety of its citizens to compel vaccinations, no one was actually compelled to receive even a vaccination against his will (although *amicus* concedes that under proper circumstances the state could demonstrate a sufficiently compelling reason to require vaccination). Instead, the Court upheld a Massachusetts statute that punished those who refused smallpox vaccination, by a fine of $5. *Jacobson v. Massachusetts*, 197 U.S. 11 (1905). There is nothing in this case to indicate any public health or safety interests the state has in compelling Nancy Cruzan's continued treatment. Consensual treatment is not demeaning or violative of individual dignity or respect for persons. But this Court has consistently recognized that involuntary, invasive medical procedures cannot be permitted absent a compelling state interest:

> When conducted with the consent of the patient, surgery requiring general anesthesia is not necessarily demeaning or intrusive. In such a case, the surgeon is carrying out the patient's own will concerning the patient's body and the patient's right to privacy is therefore preserved. In this case, however, . . . the Commonwealth proposes to take control of respondent's body [to remove a bullet that might prove him an armed robber] to drug this citizen—not yet convicted of a criminal offense—with narcotics and barbiturates into a state of unconsciousness and then to search beneath his skin for evidence of a crime. This kind of surgery involves a virtually total divestment of respondent's ordinary control over surgical probing beneath his skin.

Winston v. Lee, 470 U.S. 753, 764-65 (1985).

Nancy Cruzan's case is, of course, much worse. The state has taken permanent (rather than temporary) control of her body and has totally divested her of "ordinary control over surgical

probing" beneath her skin. It is not the unconsciousness that makes surgery demeaning in either case, it is its involuntary nature.

Rather than explore the common law and constitutional right to refuse treatment, however, the Missouri Supreme Court concludes that the state's interests *always* outweigh those of the incompetent citizen who can be treated without pain to sustain life because "the state's interest is in life; [and] that interest is unqualified." In this respect, which is at the core of the Missouri opinion, it should be noted that this argument has been consistently rejected by virtually every court that has ever heard it. Most succinctly, the Massachusetts Supreme Judicial Court has said:

> The constitutional right to privacy, as we conceive it, is an expression of the sanctity of individual free choice and self-determination as fundamental constituents of life. The value of life as so perceived is lessened not by a decision to refuse treatment, but by the failure to allow a competent human being the right of choice.

Superintendent of Belchertown State School v. Saikewicz, 370 N.E.2d 417, 426 (1977).

Amicus suggests that this proposition is also self-evident. We have historically considered life without liberty not worthy to be lived, and have set up the state to protect the liberty of its citizens. Thus the state can have no greater interest in an individual's life than the individual herself has. The inevitable conclusion follows: if Nancy Cruzan were competent, she could herself reject medical treatment needed to sustain her life.

Only two questions remain: is artificial alimentation a medical treatment?, and can Nancy Cruzan's right to refuse treatment be exercised by others, and if so, under what circumstances?

II. THE RIGHT TO REFUSE LIFE-SUSTAINING TREATMENT INCLUDES THE RIGHT TO FORGO ARTIFICIAL ALIMENTATION

Artificial alimentation is an invasive intervention using tubes or catheters and, in the case of a gastrostomy or jejunostomy, requiring surgical incision and placement of the tube. The tubes themselves are regulated as medical devices by the FDA, 21 C.F.R. 876.5980, and as used in Nancy Cruzan, fall within the government's functional definition of a life-supporting or life-sustaining device, 21 C.F.R. 860.3 (e). Regardless of whether Missouri chooses to define this device as a "procedure," "medical procedure" or a "death-prolonging procedure," it is undeniably a medical treatment. U.S. Congress, Office of Technology Assessment, *Life-Sustaining Technologies and the Elderly*, 275-329, 445 (1987) (hereinafter "*OTA Study*"); Hastings Center, *Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying*, 59-62, 140 (1987) (hereinafter "Hastings Guidelines"); President's Commission, *Deciding to Forego*, at 3.

Artificial alimentation devices or systems gain access to the alimentary tract in any of the following ways:

- by way of a nasogastric tube placed through the nose, down the esophagus and into the stomach;
- by way of a naso-enteral tube placed through the nose, down the esophagus, through the stomach and into either the duodenum or the jejunum;
- by way of a gastrostomy, endoscopically or surgically placed through the abdomen into the stomach; or
- by way of a jejunostomy, surgically placed through the abdominal wall into the small intestine.

OTA Study, at 280-282. Another form of alimentation is accomplished by way of a subclavian catheter. *Id.*, 283-286.

Even the induction of a simple nasogastric tube is no easy matter.

> Insertion of this simple plastic tube is uncomfortable and its retention is irritating. If awake and able to cooperate, the patient is asked to swallow water repetitively as the tube, which is lubricated with a tasteless jelly, is passed through the nose and pushed through the posterior pharynx and esophagus into the stomach. The tube is irritating to the nose and causes a gag reflex when it reaches the posterior pharynx, sometimes causing vomiting. The nasogastric tube continues to pose significant hazards while it is in place. It may cause vomiting and aspiration of the gastric contents, producing a serious aspiration pneumonia. It may irritate the mucosal surfaces, causing bleeding, sometimes severe. Many patients need to be restrained forcibly and their hands put into large mittens to prevent them from removing the tube, a thought which all patients with any degree of consciousness seem to have. These restrained patients may develop pneumonia and serious bedsores because of lack of activity and fixed positions. Patients with some insight are likely to become depressed or angry over being tied down.

Major, "The Medical Procedures for Providing Food and Water: Indications and Effects", in Lynn (ed.), *By No Extraordinary Means* (1989), at 25. Such methods of artificial treatment are very different from a spoon, straw, or other ways in which people normally feed themselves. *McConnell v. Beverly Enterprises-Connecticut, Inc.*, *supra*, 209 Conn. at 705, 553 A.2d at 603.

The substances that provide artificial nutrition bear scant resemblance to what most people call "food" and are listed in the Physicians' Desk Reference (PDR), a compilation of pharmaceutical references. One patient's experience illustrates the undeniably medical nature of such feeding systems.

> Originally [Nancy Jobes] was fed and hydrated intravenously, then through a nasogastric tube, then a gastrostomy tube. In June, 1985, complications with the gastrostomy tube necessitated an even more direct approach. Since then, Mrs. Jobes has been fed through a j-tube inserted—

> through a hole cut into her abdmoninal cavity—into the jejunum of her intestine. Water and a synthetic, predigested formula of various amino acids are pumped through the j-tube continuously. She has been removed to Morristown Memorial Hospital at least three times because of complications with the j-tube.

In re Jobes, 108 N.J. 394, 402, 529 A.2d 434, 438 (1987). As this description makes clear, artificial alimentation is not the same as eating.

> Administering mechanical nutrition and hydration is no picnic. It is not—like feeding and offering drink ordinarily are—close, intuitive, intimate nurturing, emotionally affecting for caregiver and recipient alike. It is not done by relatives or long-time friends, or intimates. Moreover, for resistant patients who must be restrained, it really can be indistinguishable from torture.

Landsman, "Terminating Food and Water: Emerging Legal Rules", in Lynn (ed.), *supra*, at 136. *See also*, *In re Requena*, 213 N.J. Super. 475, 485-86, 517 A.2d 886, 892 (Ch. Div.) *aff'd*, 213 N.J. Super. 443, 517 A.2d 869 (App. Div. 1986). Thus, artificial alimentation is demonstrably a form of medical intervention that patients may elect to forgo.

The vast majority of courts have decided that there is no meaningful legal distinction between artificially provided nutrition and hydration and other life-sustaining interventions, such as respirators for breathing or dialysis for elimination, and have concluded that the right to refuse treatment necessarily includes the right to refuse artificial alimentation.

> [A]rtificial feedings such as nasogastric tubes, gastrostomies, and intravenous infusions are significantly different from bottle-feeding or spoonfeeding—they are medical procedures with inherent risks and possible side effects, instituted by skilled health-care providers to compensate for impaired physical functioning. Analytically, artificial feeding by means of a nasogastric tube or intravenous infusion can be seen as equivalent to artificial breathing by

> means of a respirator. Both prolong life through mechanical means when the body is no longer able to perform a vital bodily function on its own.

In re Conroy, 98 N.J. 321, 372-374, 486 A.2d 1209, 1235-37 (1985). *See also*, *Brophy v. New England Sinai Hospital, Inc.*, 398 Mass. 417 at 435-39, 497 N.E.2d 626 at 636-38; *In re Peter*, 108 N.J. 365, 380-382, 529 A.2d at 419; *In re Jobes*, *supra*, 108 N.J. at 413, n. 9, 529 A.2d at 444, n. 9; *In re Gardner*, 534 A.2d 947, 954-55 (Me. 1987); *In re Drabick*, 200 Cal. App. 3d 185, 195, n.9, 245 Cal. Rptr. 840, 846, n. 9 (1988); *Delio v. Westchester County Medical Center*, 129 A.D.2d 1, 516 N.Y.S.2d 677 (1987); *Gray v. Romeo*, *supra*, 597 F. Supp. at 587; *McConnell v. Beverly Enterprises-Connecticut, Inc.*, *supra*, 209 Conn. at 705, 553 A.2d at 603; *Corbett v. D'Alessandro* 487 So.2d 368, 371 (Fla. Dist. Ct. App. 1986), *rev. den.* 492 So.2d 1331 (Fla. 1986); *In re Browning*, 543 So.2d 258 (Fla. Dist. Ct. App. 1989).

Implicit in the Missouri court's opinion that the law does not permit any patient to die by starvation and dehydration is the belief that patients who forgo such treatment inevitably die agonizing deaths. Given that one of the premises on which the court rests its decision to continue treatment is that Nancy Cruzan is incapable of feeling pain,[3] it is unclear how she could be pained by the withdrawal of treatment whose administration she is incapable of sensing.

If decisions about withdrawing treatment were to be premised on such loose considerations as a desire to prohibit a certain mode of dying, one might well say that patients could never refuse treatment that may result in death by suffocation (withdrawal of respirators), heart attack (cardiopulmonary resuscitation), bacterial infections (antibiotics), a rise in toxins (dialysis), or gangrene (amputation). Nothing in the Missouri Supreme

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3 Whether unauthorized contact results in pain is an important, but not a controlling issue. Unconscious, sleeping, anesthetized and even dead persons have an interest in preserving their dignity regardless of the state's ability or failure to inflict pain. The absence of pain makes the contact neither less offensive nor more lawful.

Court's opinion gives parents or guardians the authority to refuse *any* medical treatment, no matter that it provides no benefit and may even cause suffering. Natural death legislation could become death regulation, and an iatrogenic death would be substituted for a natural, progressive failure of body systems. Under Missouri's reasoning, patients would always die intubated, medicated, catheterized and amputated for the sake of preserving life. No law can make death other than what it is: for some peaceful, for others not. President's Commission, *Deciding to Forego*, at 24. By divesting patients of any choice in the matter, however, the law can make life not worth living under certain circumstances. The court's reasoning would compel treatment in pursuit of an unattainable goal—perpetual life—at the sacrifice of other, equally essential interests. If the court's concern is the legitimate one that patients not be abandoned by the medical system, that concern is met by permitting the Cruzan family to have the tube removed and transferring their daughter to the hospice section of the hospital, the very relief they originally sought.

In short, forgoing treatment does not mean that all care is abandoned. It means forgoing only a particular unwanted treatment. Hospice care provides treatment directed toward the reduction or abatement of the physical and psychosocial symptoms of a patient for whom treatment to cure or control a disease is no longer appropriate or effective. 42 C.F.R., sections 418.1 *et seq.*; Joint Commission for the Accreditation of Health Care Organizations, *Hospice Care Standards Manual* (1986). Such comfort care remains available when any life-sustaining treatment is forgone.

> When a life-sustaining treatment is forgone, and whenever a patient is dying, the treatment team has an obligation to provide supportive care, to make the patient as comfortable as possible and to assure that adequate symptom control and support will be provided. * * * Such care may include a wide variety of measures to provide symptomatic relief, sedation and pain control, skin care, and turning and positioning.

Hastings Guidelines, supra, at 30.

Thus, the use of water and dextrose in place of liquid nutrition, and of ice chips to maintain moisture, are examples of the readily available means of comfort for the patient who wishes not to be artificially fed. Dresser and Boisaubin, "Ethics, Law and Nutritional Support", 145 Arch. Int. Med. 122, 123 (1985). *See also*, Ruark, *et al.*, "Initiating and Withdrawing Life Support", 318 N. Eng. J. Med. 25, 30 (1988); Rulkin and Lukashok, "Rx for Dying: The Case for Hospice Care", 318 N. Eng. J. Med. 376 (1988); "Supportive Care for Dying Patients: An Introduction for Health Care Professionals", in President's Commission, *Deciding to Forego*, at 277-297. Steinbrook and Lo, "Artificial Feeding: Solid Ground Not a Slippery Slope", 318 N. Eng. J. Med. 286, 288 (1988); Lynn, "Legal and Ethical Issues in Palliative Health Care", 12 Seminars in Oncology 476 (1985); Lynn and Childress, "Must Patients Always be Given Food and Water?", in Lynn (ed.), *supra*, at 52-53 (1989); Schmitz and O'Brien, "Observations on Nutrition and Hydration in Dying Cancer Patients", in Lynn (ed.), *supra*, at 29-38. There are at least twenty-seven hospices available in Missouri, whose expertise is the provision of such care. National Hospice Association, *The 1988 Guide to the Nation's Hospices*, 96-98 (1988). The specter of a cruel death by "starvation and dehydration" raised by Missouri is, therefore, a myth, for as the record in this case itself shows, withdrawal of artificial alimentation does not cause the patient to suffer an agonizing end.

III. BECAUSE THESE CONSTITUTIONAL RIGHTS ARE IMPORTANT TO INCOMPETENT AS WELL AS COMPETENT PATIENTS, SURROGATE MEDICAL DECISIONMAKING IS NECESSARY TO INSURE THAT THEY SURVIVE A DETERMINATION OF INCOMPETENCY

Implicit in the concept that the right to refuse treatment is a patient's personal right is the idea that patients do not lose their rights when they lose consciousness. The rights of competent and of incompetent patients are parallel. If the state's interest in

preserving an incompetent patient's life depends primarily on the technological ability to sustain existence—what Missouri calls its "unqualified interest in preserving life"—there is no evident reason why such logic does not apply to competent patients, even to the point of restraining them in order to compel treatment. Thus, the generally accepted view that rights concerning treatment decisions do not lapse when a patient becomes incompetent is as essential to preserving the rights of competent patients as of incompetent patients.

To say that a patient's medical decisionmaking rights—including the option to forgo treatment—survive incompetency requires elaboration, since the capacity for the contemporaneous exercise of self-determination clearly does not survive. The right of privacy is often said to include three interrelated interests: (1) maintaining one's physical integrity; (2) controlling disclosure of personal matters; and (3) independence in making certain types of important decisions. *Akron*, *supra*, at 426-27; *Maher*, *supra*, at 473; *Whalen*, *supra*, at 598-600. These interests correspond to the values that informed consent encourages and protects. Faden and Beauchamp, *supra*, at 39-43; section I, *supra*. If these rights lapsed with consciousness, incompetent patients would have *no* interest in prohibiting the violation of their physical integrity, limiting the disclosure of private information, or in the nature or quality of treatment decisions or of the treatment itself. In short, they could be treated as things, not persons. These interests are, therefore, valuable to incompetent as well as competent patients, and it is hard to imagine how respect for individuals could exist if these values were discarded. The difficulty here is not whether these interests survive incompetency but how best to safeguard them during incompetency.[4]

4 Analogies to the rights governing speech, voting or marriage, *see*, Weber, "Substituted Judgment Doctrine: A Critical Analysis", 1 Issues in Law and Medicine, 131, 139-40 (1985), are specious. Nobody is obligated to speak or marry; elections are held, but people are not required to vote. For competent as well as incompetent patients, however, treatment decisons must be made. Indeed, if the analogy to other rights were accurate, its inescapable conclusion would be that absent the consent of the patient herself, treatment could never be rendered. Such reasoning would bring us to the absolute position that an incompetent patient's liberty or privacy interest may *never* be violated, since neither a surrogate, a physician nor the state could abridge that interest any more than they could compel a citizen to vote, speak or marry. Because no one would have the legal power to override Nancy Cruzan's interest in protecting her physical integrity, the current treatment would have to be halted.

It makes no more sense to say Nancy Cruzan must be treated because she cannot now say no, than to say that she should never have been treated because she never said yes. Taken to their logical extremes, neither view reaches a sensible result. Because society has an interest in ensuring that incompetent patients receive the treatment they want and need, and in respecting the dignity of all persons, an intermediate approach is essential to maintaining this balance. Surrogate decisionmaking furthers the law's respect for the rights of persons with regard to medical treatment decisions, and strives to ensure that incompetent patients may enjoy the fullest possible range of rights available to competent patients. *Rasmussen*, *supra*, 154 Ariz. at 219, 741 P.2d at 686. Unless the rights of liberty, privacy and informed consent are deemed inapplicable to incompetent patients, surrogate decisionmaking must be permitted. It is not a fraud, but a necessary legal mechanism that remains truthful to the values of life and liberty. Fuller, *Legal Fictions*, 49-53 (1967).

This Court has repeatedly affirmed that freedom of personal choice in matters pertaining to the family is one of the liberties protected under the Fourteenth Amendment's Due Process Clause. *Loving v. Virginia*, 388 U.S. 1, 12 (1967); *Pierce v. Society of Sisters*, 268 U.S. 510 (1925); *Meyer v. Nebraska*, 262 U.S. 390 (1923); *Prince v. Massachusetts*, 321 U.S. 158, 166 (1944); *Skinner v. Oklahoma*, *supra*, 316 U.S. at 541; *H.L. v. Matheson*, 450 U.S. 398, 410 (1981); *Bowen v. American Hospital Association*, 476 U.S. 610, 627 (1986); *Parham v. J.R.*,

442 U.S. 584, 602-04 (1979); *Michael H. v. Gerald D.*, 57 U.S.L.W. 4691, 4694 (1989). The law customarily defers to the family or, in its absence, to a duly appointed guardian, to act as the patient's surrogate in the event of incapacity. Health care providers assume this is so.

> If the patient/resident has been adjudicated incompetent in accordance with law, is found by his or her physician to be medically incapable of understanding or exhibits a communication barrier, these responsibilities are assured for the patient/resident by his or her guardian, next of kin, or legally authorized person.

Joint Commission for the Accreditation of Health Care Organizations, *Long Term Care Standards Manual*, 56 (1988). The family is customarily presumed to be in the best position to make treatment decisions on behalf of an incompetent child, sibling or spouse, including the withdrawal of life-sustaining treatment. Areen, "The Legal Status of Consent Obtained from Families of Adult Patients to Withhold or Withdraw Treatment", 258 J.A.M.A. 229 (1987); *In re L.H.R.*, *supra*, 253 Ga. at 446, 321 S.E.2d at 722; *In re Barry*, 445 So.2d (Fla. Dist. Ct. App. 1984); *In re Rosebush*, Mich. Cir. Ct., Oakland Co., No. 88-349180AZ (July 29, 1988); Newman, "Treatment Refusals for the Critically and Terminally Ill: Proposed Rules for the Family, the Physician and the State", 3 N.Y.L.S. Hum. Rts. Ann. 35, 44-55 (1985); Rhoden, "Litigating Life and Death", 102 Harv. L. Rev. 375, 437-46 (1988).

The Missouri Supreme Court, however, rejected as a matter of law the proposition that the right to refuse treatment may ever be exercised by any surrogate, family member or guardian in the event of incompetency, by declaring emphatically that the court cases holding otherwise simply employed a "rationale . . . born to reach the end sought."

Extensive explanations of the values underlying surrogate decisionmaking are readily available in the cases the Missouri Supreme Court relegated to a footnote. Generally, surrogate decision-making uses two standards in making treatment decisions for the incapacitated patient: substituted judgment and

best interests. Originating in the law requiring guardianships, these mechanisms protect self-determination by attempting to arrive at the same choice the patient would make if capable, and promote patient welfare by seeking to place reasonable limits on the use of unduly intrusive, burdensome or futile treatment. Ideally, courts seek clear evidence of the patient's wishes, which the trial court in fact found in this case. Where the patient has not articulated her preference, or where the testimony regarding oral statements is consistent, but not sufficiently probative, the court implements 'substituted judgment' by taking into account all that is known about the patient's beliefs and values, together with whatever is known about the treatment in question, to arrive at the decision the court believes the patient would have made. As was done below, the court seeks the guidance of family and friends, those most likely to know and be concerned for the patient. When the evidence under either of these standards is unavailable, the 'best interests' test weighs the relative benefits and burdens of treatment in an effort to balance the interest in preserving life with continued respect for the person who is the patient.[5] President's Commission, *Making Health Care Decisions*, Vol. I, 177-88 (1982); *Deciding to Forego*, at 121-96; *OTA Study*, at 118-19; *Hastings Guidelines*, at 28 (1987); *Rasmussen*, *supra*, 154 Ariz. at 221-223, 741 P.2d at 688-89; *Drabick*, *supra*, 200 Cal. App.3d at 193-212, 245 Cal. Rptr. at 844-856; *John F. Kennedy Memorial Hospital v. Bludworth*, *supra*, 452 So.2d at 926; *In re Gardner*, *supra*, 534 A.2d at 953; *Brophy v. New England Sinai Hospital, Inc.*, *supra*, 398 Mass. at 433-38, 497 N.E.2d at 631-34; *In re Conroy*, *supra*, 98 N.J. at 356-68, 486 A.2d at 1227-33; *In re Jobes*, *supra*, 108 N.J. at 413-424, 529 A.2d at 443-447; *In re Peter*, *supra*, 108 N.J. at 374-377, 529 A.2d at 423- 430. All of the cited authorities demonstrate that the Missouri Supreme Court's casual dismissal of this doctrine is destructive of individual and family values and rejects the basic principles of informed consent.

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5 Because the trial court found clear and convincing evidence of Nancy Cruzan's wishes, it did not have to consider the evidence under these tests. Because the Missouri Supreme Court's opinion precludes surrogate decisionmaking altogether, it is not known how it would implement these standards.

IV. THE REASONING UNDERLYING THE DECISION BELOW LEADS TO RESULTS CONTRARY TO THE INTERESTS THE CONSTITUTION PROTECTS AND OUGHT TO ENCOURAGE

Sweeping claims about the need to preserve life "have an emotional appeal that facilely avoids the constitutionally required scrutiny of the state's authority to act and search for less restrictive alternatives." *Public Health Trust of Dade County v. Wons*, 541 So.2d 96, 99 (Fla. 1989) (Ehrlich, C.J. concurring). Although a laudable goal, the preservation of life is not an unswerving mandate that absolutely extinguishes all other values. The decision below undermines the values that informed consent protects.

1. If Missouri's Definition of Who is Terminally Ill or Imminently Dying is Permitted to Condition Patients' Options, the Right to Refuse Treatment Becomes Meaningless.

Essential to the court's conclusion that Missouri's Death-Prolonging Procedures Act "clearly" states a policy favoring life[6] was its finding that Nancy Cruzan's case does not satisfy the statutory definition of terminal illness. Yet the only reason Nancy Cruzan is not considered "terminally ill" is that Missouri's legislature has defined artificial alimentation as a "procedure," not a "medical procedure". Mo. Stat. Ann. sections 459.010 (3) and (4). No court other than Missouri's has conditioned a patient's right to forgo treatment on satisfying the artificial definitions contained in a natural death act, or embraced the concept that treatment rights may be conditioned by verbal manipulation. *Barber*, *supra*, 195 Cal. Rptr. at 49, 147 Cal. App.3d at 1016; *Bartling*, *supra*, 209 Cal. Rptr. at 223, 163 Cal. App.3d at 193; *Corbett v. D'Alessandro*, *supra*, 487 So.2d at 370; *In re Gardner*, *supra*, 534 A.2d at 952, n.3; *In re Drabick*, *supra*, 245 Cal. Rptr. at 858-60, 200n Cal. App.3d at 214-16; *In re Browning*, *supra*, 543 So.2d at 264-270. Similarly, the logic contained in the court's observation that Nancy's death is "imminent" only if this procedure is halted, implying as it does that the state's interest in preserving life depends on medicine's ability to keep a patient alive, renders nugatory any meaningful right to refuse treatment.

6 In fact, it is not that clear. Johnson, "The Death-Prolonging Procedures Act and Refusal of Treatment in Missouri", 30 St. Louis U. L. J. 805, 824-29 (1986).

As with much of the terminology employed in this area, words such as 'terminal' and 'imminently dying' convey no definite meaning and lend little precision to clinical decisionmaking. Beauchamp and Childress, *Principles of Biomedical Ethics*, 129 (1983). Contrary to popular belief, a terminal illness is not always identifiable as such, and most patients who are dying have not been declared terminally ill. *OTA Study*, at 7; *United States v. Rutherford*, 442 U.S. 544, 556 (1979). The terminology, therefore, must be used cautiously.[7]

> [F]urther definitional requirements, such as "imminently", do little to clarify the situation. Therefore, words like "dying" are used in this Report in their colloquial sense and with *a caution against regarding them as a source of precision that is not theirs to bestow.*

President's Commission, *Deciding to Forego*, at 26 (emphasis added).

A functional definition of what constitutes a terminal condition, in order to be medically precise and respect a patient's rights, should be based on the likely prognosis in the absence of treatment, and discern whether the treatment in question has curative or restorative potential, or merely prolongs the predictably fatal progression facing the patient. *OTA Study*, at 447; JCAHO, *Hospice Care Standards Manual*, 74, 77 (1986).

Similarly, a technologically dependent definition of an imminent death or a terminal illness replaces a patient's right to refuse treatment with the "right" to refuse useless care, that is,

7 Indeed, the Missouri Supreme Court inconsistently applied the word "terminal" when discussing three different patients—Karen Quinlan, Brother Fox and Paul Brophy—each of whom was diagnosed as being permanently unconscious, demonstrating the difficulties inherent in tying these matters to semantics.

care that no responsible physician would offer. Thus, the right to refuse treatment evaporates.

> "Imminent" is never defined in law, but if death is imminent it seems that most of the potential advantages that might be gained by forgoing life-sustaining treatment would have been lost.

Veatch, *Death, Dying and the Biological Revolution: Our Last Quest for Responsibility*, 159-60 (1989). As one court has ruled, limiting the right to refuse life-sustaining treatment to those instances where death is imminent

> destroys the intent of the statute. There is no need for intervention by removing life support systems for those for whom death is only hours away. * * * It is precisely people like Harriet Hazelton, who lie between life and death, enjoying nothing of the sweetness of life, while her body slowly gives up its remaining functions . . . whom the legislature seeks to protect from the indignity of the artificial prolongation of life.

Hazelton v. Powhatan Nursing Home, Va. Cir. Ct. Fairfax County, No. 98287, August 29, 1986 (slip op. at 6), *appeal den.*; record no. 860814 (Va. Sept. 2, 1986)

If the reasoning employed below goes unchecked, individual liberties of competent and incompetent patients will be conditioned on semantics. A state could enact a statute permitting patients to refuse any medical procedure except a procedure that provides air (a respirator), sustains a heartbeat (cardiopulmonary resuscitation or a pacemaker), or rids the body of its wastes (renal dialysis); and then only when death was "imminent." This would abnegate society's responsibility and the patient's right to exercise control over technology's use, and would enshroud the healing relationship in an atmosphere of "therapeutic relentlessness" devoid of the humane purposes medicine is intended to serve and the human values governing its administration.

> [T]he power technology gives us makes it necessary to ensure that we apply it humanely and efficiently. * * * [M]isuse may not only raise the cost of health care but can harm the patient. * * * Technology poses [a] challenge even to the practitioner who masters it technically. It not only offers the means to improve dramatically the patient's quality of life, but also allows us to sustain life under conditions of great suffering.

Reiser and Anbar, *The Machine at the Bedside*, xvii (1984).

2. If Guardians Are Unable to Have Artificial Alimentation Withdrawn, Some Patients Who Might Have Benefitted from Artificial Alimentation May Not Receive It.

A decision to start or attempt any treatment, including a life-sustaining treatment, should not lock the patient into a situation as irreversible as her illness. Competent patients are permitted to begin life-sustaining treatments such as respirators or dialysis machines on a trial basis, and then gauge the efficacy and desirability of continuing with them. If guardians and physicians are unable to reverse decisions to use artificial alimentation they may become unwilling ever to begin treatment, out of the fear that if it proves undesirable, they will not be able to have it withdrawn. *In re Conroy*, 98 N.J. 321, 370, 486 A.2d 1209, 1234 (1985); *OTA Study*, 264-65 (1987); President's Commission, *Deciding to Forego*, 75.

If starting treatment is optional, stopping it must also be; the alternative view leads to perverse results.

> Accepting the distinction between withholding and withdrawing as morally significant also has a very unfortunate complication: caregivers may become unduly reluctant to begin some treatments precisely because they fear that they will be locked into continuing treatments that are no longer of value to the patient.

Lynn and Childress, "Must Patients Always be Given Food and Water?", *supra*, at 56.

Time-limited trials are often the best method of evaluating the desirability of any treatment. Lo and Jonsen, "Clinical

Decisions to Limit Treatment", 93 Ann. Int. Med. 764, 764-65 (1980).

> [T]he responsible health professional should present to the patient or surrogate the option of starting or continuing a particular life-sustaining treatment on a trial basis, with reevaluation after a specific time. Having a trial period may make it easier to evaluate a life-sustaining treatment if the effectiveness, benefits or burdens are difficult to assess in advance. It is . . . preferable to try a treatment and withdraw it if it fails, than not to try at all. A trial period may reduce the patient's fears of losing control of a treatment and "being stuck on machines". It may also reduce the emotional distress if a decision is later made to forgo the treatment.

Hastings Guidelines, at 30. In order to make certain that patients receive treatment, patients must be permitted to have treatment withdrawn. The Cruzans permitted this treatment in earnest hope that it would enable Nancy to recover; that choice should not bar the decision they have now made, based on the knowledge that she never will.

3. The Balance of Interests Struck by the Missouri Supreme Court Will Cause Treatment to be Rendered in Situations that Affront an Individual's Personal Dignity.

Nancy Cruzan did not lose her human dignity when she lost consciousness. That interest is worthy of the greatest protection available under the law, for the incompetent as much as the competent patient. The decision below is indifferent to what may have to be done in order to preserve life, and ignores the fact that modern medicine is a mixed blessing.

> In its commitment to preserve life, medical care ironically has come to symbolize a prototypically modern form of torture, combining benevolence, indifference and technical wizardry.

Starr, *The Social Transformation of American Medicine*, 390 (1987). Taken to its absolute extremes, an unqualified commitment to perpetuate life can allow treatment to become abuse. In order for treatment to proceed, some patients will be physically restrained so as to prevent them from removing whatever treatment is being administered. Strump and Evans, "Physical Restraint of the Hospitalized Elderly: Perceptions of Patients and Nurses", 37 Nursing Research 132 (1988).

Slavish insistence on providing such treatment can lead to obnoxious results, as was demonstrated in the case of Iona Bayer. Resuscitated after a heart attack obstructed the flow of oxygen to her brain for 25 minutes, she was left with permanent brain damage and no reasonable hope of recovery. Her family, knowing that she would not wish to be artificially sustained under such circumstances, obtained a court order to halt the artificial feeding then being provided through a naso-gastric tube.

After the tube was removed, Mrs. Bayer's physician ordered a feeding regimen of 20 ounces of liquid nourishment four times a day. This was deposited inside one of her cheeks and was either "swallowed," because of her residual involuntary gag reflex, or ran down her face. A tracheostomy cuff, inflated for one hour, prevented any "swallowed" food from entering her lungs. When the family returned to court to compel compliance with its previous order, the doctor argued that this manner of administering nourishment did not constitute artificial feeding. The court disagreed.

> [T]he method of feeding amounts to a "pouring" of nutrients into the respondent in a manner not significantly different than by using an artificial device such as a naso-gastric tube.

In re Bayer, No. 4131 (N.D. Burleigh Co., 12/11/87) slip op. at 8. The feeding was stopped.

Finally, a blanket prohibition against ever forgoing artificial nutrition and hydration will cause physicians to administer this treatment to some patients even in those instances where it would be futile, of no possible benefit or disproportionately burdensome.

> Sometimes even providing "food and water" to a patient becomes a monumental task. Consider a patient with a severe clotting deficiency and a nearly total body burn. Gaining access to the central veins is likely to cause hemorrhage or infection, naso-gastric tube placement may be quite painful, and there may be no skin to which to suture the stomach for a gastrostomy tube. * * * The ineffective efforts to provide nutrition and hydration may directly cause suffering that offers no counter-balancing benefit for the patient. * * * To hold that a patient must be subjected to this predictably futile sort of intervention just because protein balance is negative or the blood serum is concentrated is to lose sight of the moral warrant for medical care and to reduce the patient to an array of medical variables.

Lynn and Childress, "Must Patients Always Be Given Food and Water?", in Lynn (ed.), *supra*, at 51. As one of Nancy's physicians testified regarding the hydration care of cancer patients,

> [I]f we don't withdraw it, the edema [i.e. abnormally large amounts of fluid in the intercellular tissue spaces of the body] will cause the legs to swell to the point where they start leaking fluid through the skin and they start losing it faster than you can replace it. Tr. 335-21 to 25.

As some clinicians have observed, "caring may be better expressed by providing attention and affection than by forcing calories." Lo and Dornbrand, "Guiding the Hand That Feeds", 311 N. Eng. J. Med. 402, 404 (1984). Missouri, however, sets no limits on what has to be done to satisfy its "unqualified" interest in preserving life, or on the indignities that must be suffered in order to stave off death.

4. State Decisionmaking on Behalf of Previously Competent Patients Disenfranchises the Family and Guardians and Will Substitute State-Determination for Self-Determination by Those Who Know the Patient Best.

If surrogate decisionmaking is barred, the goal of individualized treatment decisions will be wholly divested of the values or best interests of the individual in question. Such considerations include:

> (1) the intention of the patient under existing circumstances, to the extent ascertainable from past expressions; (2) any moral, ethical, religious or other deeply held belief that would bear on the patient's probable inclinations; (3) the medical condition of the patient, including the level of mental and physical functioning; (4) the nature of the recommended treatment, including its benefits, risks, invasiveness, painfulness and side effects; (5) the prognosis with and without medical assistance, regarding expectancy, suffering and the possibility of recovery; (6) the sentiments of the family, or intimate friends; and (7) the professional judgment of the physicians involved.

See, In re Westchester County Medical Center, 72 N.Y.2d 517, 537-38, 531 N.E.2d 607, 617-18 (1988) (Hancock, J. concurring); *id.*, 72 N.Y.2d at 551-552, 531 N.E.2d at 626 (Simon, J. Dissenting). The very values important to the patient when conscious would lapse with her into unconsciousness; all treatment would be presumed to be in the patient's best interests, a presumption cast into doubt by the preceding section. Family members and guardians whose consent was sought would have no option but to consent, reducing their role to little more than a mechanistic rubber stamp for the wishes of the state. *In re Drabick*, *supra*, 200 Cal. App.3d at 201, 245 Cal. Rptr. at 849-850. Not only the dying, but even the dead might suffer. *Strachan v. John F. Kennedy Memorial Hospital*, 109 N.J. 523, 538 A.2d 346 (1988).

Some, but clearly not all persons believe that the prolongation of biological life is an absolute obligation. Sentiments on this subject are profound and diverse.

> In few areas of health care are people's evaluations of their experiences so varied and uniquely personal as in their assessment of the processes associated with dying. For some, every moment of life is of inestimable value; for others, life without some desired level of mental or physical ability is worthless and burdensome. A moderate degree of suffering may be an important means of personal growth and religious experience to one person, but only frightening or despicable to another.

Deciding to Forego at 276. A monolithic view that life is to be perpetuated regardless of a patient's desires and values is inconsistent with the pluralism encouraged under the Bill of Rights. It permits persons to be treated as things, by making the law indifferent to the consequences that result from a desire to preserve life by whatever means necessary. *OTA Study*, at 446; Callahan, *Setting Limits*, 178-79 (1987); Freed, "Quality of Life: The Physician's Dilemma", 65 Arch. Phys. Med. Rehab. 109 (1984); Keyserlingk, *Sanctity of Life or Quality of Life* (Law Reform Commission of Canada, 1979).

By dismissing individual, family and medical values, Missouri substitutes the notion of state determination for self-determination. Ironically, the very standards it rejected affirm the presumption in favor of life that the court strives to preserve, and protect patients who, unlike Nancy Cruzan, are at risk of having treatment stopped improperly. President's Commission, *Deciding to Forego* at 95 and at 184-85; *Hastings Guidelines*, at iv. For the prevailing standard—when in doubt, treat—it substituted a wholly new one: treat even when there is no doubt that treatment is not wanted, would not benefit the patient or would harm the patient.

Such a view replaces the patient's judgment of what is best with the state's, turns the notion of consent on its head and undermines the fundamental values informed consent promotes. It requires restraining the family, the patient and the physician from controlling or questioning the techniques employed in the quest for perpetual life. To disregard the values of self-determination and patient welfare as the Missouri

Supreme Court has done divests life of its fullest meaning, and preserves nothing of the values essential to a society that respects both life and liberty.

CONCLUSION

For these reasons, amicus respectfully urges reversal of the decision rendered by the Supreme Court of the State of Missouri.

Respectfully submitted,

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